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ABSTRACT

Low health literacy is a societal problem, the significance of which has been increasingly recognized in recent years by the United States healthcare community and the federal government. However, its implications have thus far garnered little attention in the field of social work. This paper examines commonly accepted definitions of health literacy and their appropriateness for the social work field. Occurrences of low health literacy in clinical settings will be examined and analysis provided as to how the social work field already addresses or might better address health literacy issues in social work training and service provision. Finally, ways in which social work can further and more formally represent client needs in cross-disciplinary efforts to address problems Will be examined. (Adjunct ERIC Clearinghouse for Literacy Education) (Author/VWL)

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Health Literacy and Social Work

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Low health literacy is a societal problem, the significance of which has been increasingly recognized in recent years by the United States healthcare community and the federal government, but its implications have thus far garnered little attention in the field of social work. This paper will examine commonly accepted definitions of health literacy and their appropriateness for the social work field. Occurrences of low health literacy in clinical settings will be examined and analysis provided as to how the social work field already addresses or might better address health literacy issues in social work training and service provision. Finally, ways in which social work can further and more formally represent client needs in cross-disciplinary efforts to address problems will be examined.

Definitions of Health Literacy

Health literacy is currently a topic of considerable interest in the medical, pharmaceutical, adult education, and health education fields. The field of social work, however, has to date produced little information on the topic. Perhaps the most broadly accepted definition of health literacy is that put forth by the National Library of Medicine in 2000 (also cited by the federal government in its Healthy People 2010 health objectives for the first decade of the 21st century):

> [Health literacy is] the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions. (p. vi)

The American Medical Association definition provides slightly more detail on skills perceived necessary for patients.

> Health literacy is a constellation of skills, including the ability to perform basic reading and numerical tasks required to function in the health care environment. Patients with adequate health literacy can read, understand, and act on health care information. (American Medical Association in Bresolin, 1999, p. 553)

A 1999 definition proposed by Nutbeam (in Kerka, 2003) analyzes levels of needed skills further, allowing social workers to see more clearly where they can be of importance to the health literacy discussion. Nutbeam's model identifies three levels of health literacy by categorizing key skills:

> (1) functional health literacy—basic reading and writing skills to understand and follow simple health messages;
>
> (2) interactive health literacy—more advanced literacy, cognitive, and interpersonal skills to manage health in partnership with professionals; and
>
> (3) critical health literacy—ability to analyze information critically, increase awareness, and participate in action to address barriers.

In Nutbeam's explanation, skill levels 2 and 3 represent areas in which social work is especially well-suited to make contributions. The areas of cognitive and interpersonal skills for interaction, life skills needed for daily functioning, and critical thinking skills to raise awareness and solve problems, represent domains in which social workers are already actively working in a variety of practice settings to help clients develop in themselves.

The NLM and AMA definitions are broad and leave ambiguous what is meant by functioning in the health care environment and making appropriate health decisions. Nutbeam's definition, though more specific, leaves equally ambiguous the notion of

appropriate functioning. Do the definitions seek to imply that the patient is knowledgeable enough to advocate for himself and determine his own preferred course of action, or do they seek to indicate that the patient is in compliance with the desires of health care providers?

Social workers might also benefit from considering a definition from adult literacy, a field whose clients share many characteristics with social work clients. Many come from backgrounds of poverty, educational disadvantage, low self-esteem, substance abuse, and domestic violence. Many have limited English. Adult literacy learners are often unaware of, or have difficulty accessing or understanding various systems from which they might draw assistance or support. Seeking health care in the U.S. health care system presents considerable challenges to many in the adult education population. The challenges arise not just with basic literacy skills, but with communication skills, self-advocacy skills, cultural awareness, understanding of practitioner and patient roles, problem-solving skills, and general awareness of health care resources and legal rights. A definition proposed by Singleton (2003, p. 5) for the field of adult literacy provides a more detailed parsing of health literacy which might be helpful for social workers. The definition attempts to explain health literacy as it relates to adult literacy learners, giving focus to personal health choices and beliefs as well as interaction with the U.S. health care system. Singleton writes:

> Health literacy is the knowledge and skills needed to:
>
> - Be aware of one's own health beliefs and practices.

- Make personal choices about health and health care options. (This could mean, for example, opting for cultural or traditional forms of care over seeing a U.S. health care system provider, or opting to combine cultural or traditional and mainstream U.S. approaches.)

and within the U.S. health care system, to:

- Read, understand, and act upon medical instructions, forms, and labeling.
- Learn about medical conditions and treatment options through printed materials (including video and the Internet) and oral description by a health care provider, especially for those conditions for which the learner is most at risk.
- Read, understand, and act upon payment-for-care instructions and forms.
- Orally communicate questions and concerns to health care providers; understand their responses or request clarification.
- Access local affordable preventive, primary and emergency care.
- Seek a reasonable means for one's financial resources of paying for care (request insurance, public benefits, payment plans, reduced fees, etc.).
- Appeal decisions relating to payment-for-care orally (by telephone) and in writing.
- Understand what U.S. health care culture expects of patients (such as preventive care behaviors, personal responsibility for health care and payment for care, being proactive in seeking care and making care-related decisions, questioning the health care provider, keeping track of medical history, understanding complicated financial options and procedures, etc.).

- Understand what the patient can expect from health care providers in the U.S. health care culture, such as the patient's right to an interpreter, the right to have questions answered and information clarified, and the right to a second opinion.
- Request interpretation assistance for health care settings if English is not the learner's native language.

(Note: 'Medical' and 'health care' in the above definition refer to physical and emotional health.)

What Social Workers Are Already Doing

While teaching basic literacy skills of reading, writing, and the English language is beyond the purview of social work, other skills in Singleton's definition are well-within the norms of social work practice and support social work goals of client self-empowerment and self-advocacy, increased access to needed services and resources, and equity. Within the context of various practice settings, social workers can and do help clients to

1) Identify client's own perspectives and beliefs about health and health care
2) Make choices that are in keeping with those views
3) Understand basic information about preventive care, health conditions, and treatment options through language and formats that coincide with clients' literacy level and culture.
4) Understand the dynamics of interpersonal relationships (such as the client's relationships with health care providers and how health situations affect the client's relationship with family members, and vice versa). In health care situations, the dynamics of individual relationships may be affected by

culture, language (even when provider and patient are both native English speakers, due to the highly technical communication style preferred by some providers), socioeconomic status, education, and many other factors. Misinterpreted communications, beliefs and actions between patient and provider can impede the client getting adequate care for their needs and beliefs.

5) Practice communication skills that support self-advocacy and self-determination through role-play and other techniques. In the health care arena this can include how to ask questions about conditions and proposed treatments, how to request simplified patient education materials or explanations that are not in written form, how to request second opinions, how to request financial assistance, or how to request interpretation assistance.
6) Identify compensatory strategies for areas in which the client has a perceived or real limitation. In a health care situation, this might mean bringing an advocate along to appointments, making lists of questions and concerns in advance, devising ways to remember and adhere to drug regimens when written instructions are insufficient, etc.
7) Identify affordable sources of care for which they qualify. This might mean, for example, being referred to a free clinic or applying for Medicaid.
8) Set up payment for care in ways that are manageable for the income and unavoidable expenses of clients. Learn how to make a budget to allow for regular payments of manageable installment plans.

9) Increase awareness of one's rights and responsibilities in the role of patient, and the rights and responsibilities of others in the role of health care providers.

Many of the above issues can be culturally or personally challenging and fraught with emotional difficulty for clients. Asking for financial assistance is potentially embarrassing for some. Revealing low literacy skills can be devastating to an adult's self-esteem. Communicating with (and potentially demonstrating one's ignorance to) a professional person who has more education and higher socioeconomic status can be inhibiting as well. A social worker can help clients to understand what they personally find difficult in these situations and can help develop strategies to decrease the challenges.

Accounts from different social work practice areas demonstrate that social workers often find themselves addressing physical health and health care education needs with their clients. For example, social workers in an HIV clinic report helping clients to understand medication adherence and safety; basic nutrition; safe sex practices; how to communicate questions, needs and concerns to health care providers, and how to manage medical bills. Social workers educate clients on health topics even outside of health-focused practice environments. A high school social worker educates her clients on the effects of alcohol and drug abuse on the body, how to use contraception, and the benefits of exercise, good nutrition, sunlight and fresh air on brain chemistry. A bereavement support group facilitator reports educating her clients on methods of stress management and self-care and has helped some clients to decrease frustration and improve communication with health care providers. Another social worker who has worked in various capacities with homeless families and people who have severe mental illness and

has helped educate many clients who had little understanding of basic health care, who did not have health insurance coverage, or who were confused and frustrated by Medicaid, Medicare, or state children's health insurance applications and policies. A social worker who worked with clients with schizophrenia educated a client on dental hygiene and its importance to his overall health. While all these social workers were addressing health literacy needs of their clients, none knew of the formal concept of health literacy or of efforts to address it in the medical and educational fields (personal communications with L. Burdick, D. Kaye, M. Scherzer, L. Storms, E. Sumser, & S. Yano; March 4-14, 2003).

Suggested Health Literacy Training Support for Social Workers

Should health literacy training be made available only to social workers in health care settings, or to all social workers? Physiological needs are the most basic on Abraham Maslow's Hierarchy of Needs. When they are having difficulty taking care of physical health needs, clients are less able to focus effectively on other issues for which they are in treatment or case management. As was seen in the above cases, physical health issues come up in all kinds of social work venues.

While the workers from various practice areas who were described above were able to provide help to their clients in areas relating to health literacy, they reported uncertainty as to how best to educate their clients and to what degree they should engage in this educational role as part of their work. With limited formal examination of the bio component in graduate level social work education and the multiple dimensions that make up an individual's health beliefs, practices, and experiences; busy social workers, especially those in a non-healthcare-focused practice area, may draw primarily and

underconfidently on their personal experiences and limited knowledge of health and health care in selecting health information to impart to clients. This might lead to misinformation, insufficient information, or inappropriate information for the client's personal situation. Increased bio education might help workers to be more confident in seeking appropriate health information and advocating for their clients.

There are other compelling reasons to strengthen social workers' training around health and health literacy. Rita Webb, DCSW, Senior Staff Associate for Health for the National Association of Social Workers (NASW), reports in Fiske (2002) that due to health care field downsizing, many positions typically held by health care social workers have been lost. This may consequently result in clients with health care needs falling through the cracks, not knowing what care they need, or how to access affordable initial care or follow-up care for a health issue. Are such people being seen by social workers for other community services? Do non-healthcare social workers have sufficient knowledge to recognize health issues in these clients? Are sufficient appropriate health-related referrals being made?

Clinicians in all practice areas can benefit from increased awareness of literacy and health issues that might affect their clients. Below are some suggestions for supportive training content.

On Adult Basic Literacy

While literacy instruction is not part of social work, it would be beneficial for all social workers, and especially those who work in the health care arena, to receive basic information in their training about the scope of low literacy among U.S. adults, what its effects are, and how adults with low literacy perceive their situation. For an example of

scope, the most recent National Adult Literacy Survey (NALS) gives the following statistics:

1) 50% of welfare recipients read below the 5th grade level,
2) 50% of Hispanic Americans and 40% of African American adults have low literacy skills (Center for Health Care Strategies, 2003), and
3) The majority of adults with low literacy are white Americans (Bresolin, 1999).

Based on NALS data, the American Medical Association (Bresolin, 1999) reports that nearly half of all adults are believed to have low health literacy, that is, insufficient reading and writing skills to function well in health care settings. Historically, health information, including informational brochures which social workers commonly distribute to clients, has been written to target adults with a high school reading level, beyond the average adult literacy level (Hohn, 1998). The disconnect between client reading and writing skills and the reading and writing demands of printed materials social workers commonly distribute no doubt does not occur to many busy social workers.

Some social workers may assume that their clients feel comfortable enough to reveal literacy barriers to them, or that the workers can readily identify low literacy in a client. These assumptions are not necessarily true. Many adults with low literacy feel great shame about what they perceive as a personal deficit. Many develop strategies to fool others into thinking they are more literate, such as saying they will read a document at home when they have more time, saying they forgot their reading glasses, or simply acknowledging comprehension of a document and signing it, when in fact they were unable to read it. Undoubtedly many social workers can enhance their service provision

by becoming more aware of these patterns and working to engage the client's trust around the issue of literacy. If literacy obstacles are found, workers and clients can co-design strategies for circumventing problems, such as having agencies provide appropriate easy-to-read printed materials. Workers can also advocate as needed on behalf of their clients for literacy assistance from others who serve the clients, such as clinics and hospitals.

On Health (The Bio Component)

Educating clients has been recognized as one role of social workers for some time (See, for example, Compton & Galloway, 1989, 509-510; Locke, Garrison, & Winship, 1998, 197-201.) Psychoeducation, for example, has been recognized as a standard component of social work in various practice settings for some time. Education relating to physical health and health care, however, has not been practiced by social workers to as great a degree. While modern social work is credited with a biopsychosocial and spiritual approach, attention given to biological concerns of clients is far less formal than other dimensions, with the exception of work done by social workers specifically within health care settings. As mentioned previously, while social workers outside of health care settings encounter health and health care issues among their clients with some frequency, the workers don't always feel confident in their knowledge and experience to educate and refer clients around these issues.

Saleebey (1985, 1992) and Johnson et al. (1990) are among those who have argued for the importance of including more biological content into social work training. They cite the need for increased biological knowledge so that social workers can make more appropriate referrals and treatment recommendations, can recognize inappropriate

treatment of clients by physicians, and can advocate for clients with medical and psychiatric care providers. They stress the interconnectedness of body and mind as a respected principle among social workers, but emphasize that to support holistic practice workers need more knowledge of what body and mind are individually capable of and how they can affect each other. Saleebey also suggests that increased biological knowledge would decrease law suits against social workers.

Johnson et al. (1990) and Hutchison (1999) stress that it is unfeasible to expect social workers to gain a complete understanding of how the body works, and it is unreasonable to expect social work graduate programs to attempt to incorporate such material into already crowded curricula. However, Johnson et al. suggest that educators focus on imparting to students a method for finding biological information rather than mastering the biological information itself. In the 13 years since the publication of their article, the presentation of abundant health information for lay readers on the Internet has made this task much more manageable. Method over material makes sense when one considers the vast array of health situation in which clients might find themselves. It is more practical for a social worker to look to reliable resources for a topic currently at hand than to try to master understanding of a multitude of biological functions and conditions.

In the years since the Saleebey and Johnson et al. publications, social work has increased awareness of cultural sensitivity and competence. In health literacy training for social workers, it is important to emphasize that health is a culturally defined concept, and different clients view health and treatment for health situations differently. Social workers who do not have this awareness may fail to consider diverse perspectives in

helping clients identify care options. They might overlook health traditions and beliefs held by clients which could conflict with workers' and/or mainstream U.S. health care perspectives. For example, *overemphasis* of the biological model of health might turn off a client whose culture emphasizes spirituality or energy balance as the main components of health. A culturally aware worker might help the client find ways to address a health issue with a blend of U.S. mainstream and alternative methods of treatment, or might find that the client is better off pursuing alternative methods alone. Again, it is unreasonable to expect social workers to master a broad array of cultures' beliefs on health. Becoming familiar with and practicing use of available resources, as well as practicing to elicit cultural information directly from the client, might strengthen worker awareness sufficiently.

On the Mainstream U.S. Health Care System

As the mainstream U.S. health care system is the source of care with which most public and private health insurance coverage works, for better or worse it is the system in which most social work clients seek health care. Social workers need to have a fair knowledge of how the system and its various subsystems function in order to instruct clients about it and advocate for them in it. This system, as all systems, has a culture of its own with rules and role expectations for those who participate in it. It is rapidly changing and the skills needed by patients to navigate it and advocate for themselves are growing increasingly complex. For example, as patient loads and time pressures on health care providers increase due to managed care constraints, patients are expected to be more assertive and ask more questions of providers, with less time to formulate and ask the questions. They are also expected to learn more about health independently from

such tools as the Internet and patient education brochures, and to navigate complex systems of referral, preferred medication lists, and bill payment. It is important that social workers have a broad enough understanding of this system -- an understanding that encompasses its structure, functions, political and financial components -- to be able to help clients navigate it and build self-advocacy skills.

Again, the worker needs to be aware of clients' cultural beliefs on health and health care to assist them in their understanding of the U.S. system. If clients are coming from countries with different forms of health care provision, or if they are from the U.S. but have had little personal contact with the U.S. system, they might hold vastly different expectations for patients and providers. Unaware workers might encounter difficulties if, for example, they overlook a client's cultural beliefs in such areas as the role of the individual vs. the family in healthcare decision-making. Also, they might fail to consider the level of trust a client carries for health care professionals. Problems might ensue if the client puts complete faith in a provider because in the client's native country (or with clients from older generations in the United States) the doctor isn't to be questioned. Similarly, problems might also ensue if a client must work closely with a doctor but comes from a cultural background in which doctors are historically not trusted. If workers omit or downplay such issues in health-related discussions with clients, clients could experience extra stress and conflict over health and health care decision-making.

Of course, training on the health care system (or any of the health-related issues discussed in this paper) need not occur solely in graduate social work programs; it should also occur in practice settings. This is supported by NASW's ethical principle which directs social workers to "continually strive to increase their professional knowledge and

skills and to apply them in practice" (NASW, 1999). Social workers already in practice no doubt have much insight to offer one another in the area of health literacy based on their individual experiences at tackling client health-related issues as they arise. As agencies become more formally aware of low health literacy's impact on clients, workers can pool their knowledge and educate one another. Also, social workers who have helped clients with health literacy-related issues outside the healthcare social work domain probably have interesting perspectives to offer their colleagues within that specialty.

Proposed Directions for Social Work in the Health Literacy Arena

On the level of individual client service, social workers must continue to assist clients to problem-solve; develop communication, critical thinking and self-advocacy strategies; and increase awareness around health and health care issues. As the field becomes more aware of the impact of low health literacy, no doubt workers will broaden their applications of interventions in these areas. Hopefully workers who have previously felt that physical health is not an appropriate domain for social workers will start to understand that social workers do in fact have important educational and advocacy roles to play in health and health care issues.

Social workers seem especially well-suited to expand their role into interdisciplinary approaches to the problem of low health literacy. Social workers can promote a multidimensional understanding of the concept of health literacy and the factors that contribute to low health literacy. Medical and pharmaceutical field approaches are grounded in the more pressing concerns of those industries, such as promoting treatment compliance and safe medication usage. Many efforts to promote

health literacy from within those industries aim at symptoms of the problems and overlook root causes, such as cultural differences in health beliefs, differing expectations on the part of care providers and patients, differing modes of communication at work between providers and patients, historical mistrust of healthcare professionals, and a range of social inequities that lead to lack of access to timely, appropriate and affordable care. Social workers, who are historically adept at cross-disciplinary collaboration and advocacy, can take steps to insure that these factors are introduced into interdisciplinary discussion and kept there.

While existing approaches to health literacy promotion often tend to put the onus on the patient to fix what is wrong in health communication, social workers can reinforce that communication and cultural sensitivity problems need to be addressed by all parties involved. The notion of treatment compliance as it is currently presented within the mainstream U.S. health care system paints the provider as indisputably in the right and the patient who is "noncompliant" as wrong and disobedient, when in fact the patient may hold different health and health care beliefs and values which need to be taken into account when treatment plans are being designed. Social workers can help other helping fields to see that a patient may be "noncompliant" for a number of valid reasons, which can be addressed in ways that allow the patient dignity and respect. Also, social workers can help to remind other health care professionals of all the emotions and stressors that patients experience when they feel physically unwell, which are further intensified when the patient is facing a major medical treatment or procedure. In spite of the patient's best intentions, these factors can impede one's concentration, focus, memory, and ability to

clearly formulate questions and report information accurately, all of which can be misconstrued as signs of non-compliance or low health literacy.

All of the NASW ethical principles (NASW, 1999) and core values which guide social work in the United States speak to the participation of social workers in efforts to assist those with low health literacy. Low health literacy is a social problem, and NASW posits that the primary goal of social workers is to serve those in need and address social problems. As NASW's ethical principles suggest, social workers are well-versed in challenging social injustice. Low health literacy and the right to appropriate, affordable health care are certainly social justice issues. Adults with low literacy are often the victims of educational inequities determined by socioeconomics. Lack of socio-economic and educational opportunity keeps them from health care, or if they can access care often causes misunderstandings which lead to potentially life-threatening mistakes in their treatment.

The ethical principle promoting the worth and dignity of the individual has strong significance in the low health literacy issue. Patients with low health literacy are on the outside of the health care system looking in. Even if they can access care, their lack of education and biological health awareness, or lack of English language skills, often lead to lack of a common language to speak with health care providers. In rushed medical settings, staff may be impatient and curt with them because the patients don't immediately understand. Decisions are sometimes made for them because they are believed incapable of understanding the ramifications of their choices, and because, simply put, it is believed cheaper and quicker to not make the effort to convey information more clearly. Health beliefs they might hold from outside of the system may

be disdained or ignored. Social workers can play an important role in advocating for the dignity and self-determination of such patients.

To be fair, the health care community is making efforts to educate its own on the need for simplification of oral and written communication in health care. However, the size of the professional community in need of this education is immense, and habits of technically weighty communication long taught in medical schools will take time and effort to undo. Social workers, who often find themselves working in tangent with health care providers, can use these professional relationships to educate providers on health literacy and the multiple dimensions that feed into the patient's health beliefs, practices, and adherence to medical regimens; as well as suggesting communication strategies that could help providers and patients communicate more effectively with each other. On a macro level, social workers can make efforts to join consortiums of organizations of health care providers, health educators, and government that are already in place and working to addressing low health literacy. In addition to educating providers on the above issues, social workers can use these public forums (and other political ones) to advocate for increased public and private funding for health literacy initiatives.

Conclusion

Health literacy is effectively defined for the social work field with a multidimensional definition such as Nutbeam's, which, in addition to basic literacy skills, emphasizes communication and problem-solving skills needed to successfully manage one's health and utilize health care. Social workers are well-suited to the role of promoting health literacy awareness in the United States. Their core values and guiding ethical principles fully support efforts to help clients with low health literacy at micro and

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